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ABSTRACT

This booklet defines chronic health-related illnesses and how they affect life functions; discusses the importance of transition planning; identifies how parents, school personnel, medical personnel, and community service providers can help the students with a chronic illness gain the knowledge and skills necessary for a successful postsecondary outcome; and lists elements of effective transition planning. The goals of a transition plan are defined and include the student's ability to: identify the impact of the illness on his or her life; determine what the impact of the illness may be in the particular postsecondary setting; and develop and implement strategies to minimize or alleviate this impact in order to increase the opportunity for success. The role of disability support services staff in helping prospective students identify how illness may impact the experience at that particular higher education institution and decide on appropriate accommodations is also discussed. Finally, factors that students should assess when choosing an institution are described and include assessing: the college's ability to meet academic needs, community services at the college's location, the college's ability to meet disability-related needs, health insurance coverage, and financial needs for education. Contains a list of organizational resources and a list of two publications that focus on postsecondary institutions and disability laws. (CR)

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ED 418 562

HEATH Resource Center

Maximizing Success for Young Adults with Chronic Health-Related Illnesses

Transition Planning for Education After High School

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The staff of the Adolescent Employment Readiness Center (AERC) have provided employment and educational assistance to more than 1,000 students with chronic illnesses. The students often have little understanding of their illnesses, limited self-advocacy skills, and little or no knowledge of how to identify and address illness-related needs. It became increasingly apparent to the staff that for these students to have a successful higher education experience, they would need to acquire certain skills and specific information prior to moving into the postsecondary setting. It also became clear that parents or significant adults' roles in the education, environmental control, activities of daily living, and medical management of their offspring sometimes slowed the student's ability to develop the skills and knowledge necessary to assume self-management. Further, the students often were unclear about how to find a postsecondary option that would meet their needs. Many asked for assistance in locating schools that were "good" for an individual with their particular illness (e.g., diabetes, sickle cell, arthritis) rather than those that could meet their educational goals. Many students with chronic illnesses encountered difficulties once in a postsecondary setting; this was true especially of those students who lacked information about laws that protect adults with disabilities, community services available to adults with disabilities, and the resources, services, and accommodations available to students with disabilities. This lack of information and inability to develop coping strategies in postsecondary settings often results in students dropping out of the educational program, reduced higher education degree attainment, and diminished capacity for employment.

With funding from Ciba Pharmaceutical, and in conjunction with the HEATH Resource Center of the American Council on Education, the staff of the AERC sought to determine the elements necessary to develop and implement effective postsecondary transition plans. They interviewed campus Disability Support Services (DDS) staff members throughout the nation, college students with chronic illnesses, and experts in the field of disability and education.

This paper defines chronic health-related illnesses and how they impact life functions; discusses the importance of transition planning; identifies how parents, school personnel, medical personnel, and community service providers can help the student with a chronic illness gain the knowledge and skills necessary for a successful postsecondary outcome; and lists elements of effective transition planning.

Effective planning for transition to a postsecondary setting incorporates activities that facilitate the development of skills and the acquisition of information necessary for independence. These activities must be initiated early and must be encouraged throughout adolescence. The ultimate goals of a transition plan include the student's ability to:

- Identify the impact of the illness on his or her life;

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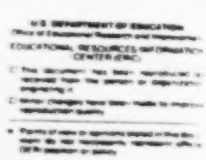

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- Determine what the impact of the illness may be in the particular postsecondary setting; and
- Develop and implement strategies to minimize or alleviate this impact in order to increase the opportunity for success.

CHRONIC HEALTH-RELATED ILLNESS

A "chronic health-related illness" can be defined in many ways. In the broadest sense, a health-related illness affects the individual for at least three months and is likely to continue in the future. Because it undermines the general health of a person, a health-related illness also may be called a chronic illness or chronic health condition. An individual may be born with the illness or may acquire it during childhood or adolescence or even later in life. A chronic illness may become a disability—either physical or mental in nature—when it substantially limits a person's major life activities. Chronic illnesses include asthma, sickle cell disease, cancer, arthritis, and others.

According to the HEATH Resource Center's *College Freshmen with Disabilities—A Triennial Statistical Profile (1995)*, nearly 25,000 students (16 percent of full-time/first-time entering college students with disabilities) identified themselves as having a health-related disability. These disabilities may range from severe allergies, arthritis, asthma, cancer, cystic fibrosis, diabetes, epilepsy, heart disease, immune deficiency, and kidney disease, to lupus, multiple sclerosis, muscular dystrophy, sickle cell anemia, and many other conditions. The actual proportion of freshmen with health-related disabilities may be much larger, because many individuals with such conditions do not self-identify.

Chronic illnesses typically are invisible to others, often are not considered a disability by those with the illness, and generally are not known to those with whom an individual with a chronic illness interacts. According to laws including the Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973, especially Section 504, a person with a health-related illness may be considered a person with a disability when the illness limits one or more life activities, such as breathing, feeling, walking, or self-care.

Even if they do not consider themselves as having a disability, people with chronic illnesses face many challenges, especially when accommodating the effects of illness in their daily activities and when entering a new setting, such as a college or university. These challenges need not be barriers. With self-knowledge, an understanding of transition issues, and the use of appropriate accommodations, individuals with chronic health-related illnesses can succeed in postsecondary education.

Variations in the severity, course, and frequency of problems relating to chronic health conditions necessitate a broad definition of health-related illness. This also suggests the need to plan for potential change in the illness and its effect on the person's ability to function. A person with a chronic illness may be without symptoms for many years and then may progress rapidly toward having a significant disability; this often happens with diabetes or the progression of HIV to AIDS, for example. Planning for the future effect of one's illness is key to making a successful adjustment. This planning, which includes identification of health-related needs and accommodations, is central to success in the postsecondary educational setting.

Impact of Health-Related Illness on Life Functions

Chronic illnesses affect individuals in many ways. Some individuals are affected only minimally by chronic illness. For example, a person with severe allergies may experience little or no inconvenience or discomfort when using medication. Someone with asthma may need to use an inhaler before or after physical activity, but is not restricted from the activity. Yet for others, a chronic illness can be life altering, necessitating specialized medical treatments and regimes. Someone with kidney disease may have to be hospitalized for dialysis; someone with AIDS may have to take myriad medications and "drug cocktails" with specific foods at specific times of the day; someone with sickle cell may experience an incapacitating pain crisis resulting in hospitalization. All of these scenarios involve substantial impacts on the individuals' activities. Other illnesses are progressive and require accommodations over time. An example is multiple sclerosis, which may have a minimal impact at the outset and yet may result in total incapacitation. In other instances, a change in environment or routine may affect one's functioning. A student with asthma, which previously has had little impact on life functioning, may find that the physical demand of walking across campus in heat or cold causes an increase in the frequency and severity of attacks. All too often, students who have not required accommodations in the past fail to anticipate potential scenarios until a health crisis develops and the need for accommodation is evident and urgent.

Proactive transition planning enables the individual to anticipate potential crisis situations and solutions, and results in less time lost from school and

other pursuits. Effective planning ensures the ability to identify how the illness currently affects one, how it is currently accommodated, and how it may affect one in the future. In this way, strategies can be developed to maximize success.

TRANSITION

Transition is an ongoing process of moving from one activity to the next. For students with chronic illnesses, transition planning is the process of anticipating illness-related needs that will impact activities of daily living, educational success, and health maintenance in the postsecondary setting, and developing strategies to minimize or alleviate them. Early adolescence is not too soon to begin acquiring needed information and skills, formulating career goals, and thinking about the postsecondary education that will be needed to achieve those goals. Also, it is not too soon to begin transition planning.

The Importance of Transition Planning

Over the past 25 years, medical and technical advances in the industrialized world have dramatically increased the probability of survival for young people with health-related illnesses. In the United States today, one of every five children and adolescents has some form of chronic illness, and more than 80 percent will survive into adulthood (Blum 1992). In the past, these individuals often did not survive beyond childhood, so responding to their immediate medical needs and keeping them alive were the priorities. Planning for the future often seemed unnecessary. Yet with extended life expectancy and the passage of laws such as the Americans with Disabilities Act, long-term goals involving postsecondary education and employment are now considered attainable.

Education and training after high school are especially important for young adults with chronic illnesses. It has become common knowledge that education and training beyond high school result in higher wages and better benefits. And because health care is critical for individuals with chronic illnesses, employment that provides health care benefits or the ability to buy health insurance is vital. Postsecondary training greatly increases the probability of such employment. Thus, it is important that young adults with chronic illnesses plan for and successfully complete postsecondary education. Developing and implementing a sound plan for the transition from high school to the postsecondary setting is key to that success.

An effective transition plan for students with health-related illnesses must address the impact of the illness on four important areas of life:

- Education;
- Environmental considerations;
- Medical needs; and
- Activities of daily living.

Education: The ability of a student to attend grades kindergarten through 12 and to participate in school activities is important to the student's overall success. Consider a student with cystic fibrosis. He or she may have frequent absences from school because of the need for hospitalization—sometimes for weeks at a time. Such absences clearly can affect a student's ability to learn, complete assignments, and take and pass exams. Such students' grades may be affected, as well as their ability to participate in school-based programs and to interact with peers. Because the spectrum of chronic illness is so broad and the symptoms of chronic illness are so diverse, the impact on education can range from minimal, to loss of credit, to necessitating home schooling. By law (Individuals with Disabilities Education Act [IDEA] and Amendments to the Rehabilitation Act of 1973—especially Section 504), elementary and secondary schools or parents of children with chronic illnesses must identify students with disabilities and the school must provide accommodations for those whose health affects their education. Students are entitled to accommodations when health-related issues interfere with their educational success.

Health-related illnesses also can affect students' participation (and success) in postsecondary education. Whereas in grades K through 12, the student may have been "entitled" to accommodations, there are no entitlements in the postsecondary environment. Students with disabilities must identify themselves to be eligible for services, must present documentation of their disability, and must request necessary accommodations. Thus, such students must know their rights. They also must know how to identify illness-related needs, develop strategies, and seek accommodations.

Comprehensive transition planning for young adults with chronic illnesses is rarely done in the high school setting. It is therefore important for students and their families to understand the impact of the illness in the high school setting and to be able to visualize its potential impact in the postsecondary setting. See "Elements of Effective Transition Planning" (page 6) for a list of questions pertaining to the

impact of a chronic illness on educational needs in the postsecondary setting.

Environmental Considerations: A student's chronic illness may itself be affected by the conditions in which the student lives and thus may dictate certain environmental considerations. In grades K through 12, the home and school environments are fairly consistent. Travel is usually limited to the trip between home and school; exposure to the elements is minimal. Classes typically are within one building. Accommodations may be made accordingly.

In contrast, the student in a postsecondary setting may travel not only to school, but also may have to walk from a parking lot or bus stop to one or more buildings over the course of a day. The student may require environmental accommodations in multiple locations. In addition, the student who chooses to live on campus may be affected differently from how he or she was in the home environment. *College Freshmen with Disabilities* reports that 65 percent of students with disabilities expected to reside in a college dorm. A student with arthritis may then have to consider living arrangements with few steps and little exposure to heat and cold, for example. Depending on the illness, a variety of environmental considerations may have a significant impact on the student. Negotiating solutions in each of these environments may involve several people and complex strategies. See "Elements of Effective Transition Planning" (page 6) for a list of questions relating to illness-related environmental needs in the postsecondary setting.

Medical Needs: A student's medical needs may have a direct impact on his or her educational success. Health-related conditions may precipitate absences due to illness, hospitalization, therapies, and the effects of medications. They also may result in activity restrictions that may impact postsecondary success. For example, a student with asthma and allergies may have many restrictions on physical activities at various times throughout the year. Such a student may require extra time for breathing treatments, or for the administration of medications. An early morning class may not be suitable for the student who requires breathing treatment. Depending on the location and climate of the postsecondary institution, as well as the nature of the student's illness, treatment regimens may greatly impact the student. It is therefore important that the student request appropriate accommodations. See "Elements of Effective Transition Planning" (page 6) for a list of questions pertaining to illness-related medical needs in the postsecondary setting.

Activities of Daily Living: Prior to a student's matriculation at a college or university, parents, friends, teachers, personal care attendants, and many others may have assisted with the establishment and carrying out of specific routines, such as bathing, dressing, eating, using the bathroom, and taking medication. The student now needs to determine whether current routines will work in the new postsecondary setting. If new routines will be necessary, the student needs to determine how they will be carried out. For example, someone living with HIV may be on a complex schedule of many medications, each needing to be taken at different intervals, with and without food. Although the student may have set up a schedule to accommodate this regimen at home, as he or she enters the postsecondary setting, the student will need to examine the impact of a different schedule every semester on this complex regimen and make adjustments accordingly. This may require very close coordination with the student's primary HIV specialist. If a student requires assistance in any activity of daily living, it will be important that he or she ensure that such assistance can be provided in the postsecondary setting. For a list of questions to consider regarding activities of daily living in the postsecondary setting, see "Elements of Effective Transition Planning" (page 7).

PARTNERS IN TRANSITION PLANNING

Many individuals can make important contributions to a student's efforts to cultivate the skills and knowledge necessary to develop an effective postsecondary transition plan. The student is always central to the plan, but parents, school personnel, community service providers, campus DDS staff, and medical personnel can help ensure that the student has the knowledge and skills necessary for developing and implementing the plan.

Students

Students without health-related illnesses have many opportunities to participate in activities that help them develop the skills they will need in the postsecondary setting. Age-appropriate experiences such as baby-sitting, feeding animals, mowing lawns, walking dogs, clerical work, delivering newspapers, participating in extracurricular activities (including sports and volunteer or paid work), socializing with friends, and meeting expectations at home and in school are a natural part of growing up. These experiences help students learn how to take responsibility for self, interact with others, advocate to have needs

met, and function independently. These opportunities may be available to all students, but the participation of students with chronic illnesses often is limited due to their illness. For some students, taking responsibility for health care regimens and learning about their illness and necessary accommodations may be the most important activity to undertake while in high school. Nevertheless, students should strive to participate to the best of their ability in as many age-appropriate activities as possible. The skills learned by participating in these activities will enhance students' abilities to implement transition plans and improve their ability to succeed in the postsecondary setting.

Parents and/or Other Significant Adults

Most children with chronic illnesses have parents or other significant adults who invest a great deal of time and care in maintaining their child's health status. Most parents assume the responsibility for their child's health maintenance and for ensuring that all needs related to the illness are met. Parents' desire for their child to maintain his or her health may inspire them to prohibit the child from participating in any activity which might have an adverse effect on health. Restrictions also may take precedence over preparing the student for future independence. Such preparation includes helping the child learn to identify needs, to advocate to have these needs met, and to have accommodations put in place in the school environment.

As their child matures, parents may be reluctant to allow him or her to assume responsibility for health maintenance. Often this is because the parents fear that if the child does not follow through, his or her health will suffer. Parents also may be reluctant to abdicate their advocacy role at school because they do not want their child's education to suffer. Thus, even though parents should help their child become increasingly independent, they often fail to do so. Parents may work to ensure their child's health and educational success while he or she is at home, but the resulting dependence ultimately can make it difficult for the child to function independently in a postsecondary setting.

To ensure that family members promote the skills necessary for effective transition planning, they should:

- Encourage activities that promote the adolescent's ability to identify illness-related needs, understand and assume his or her rights, and develop strategies to minimize or reduce the impact of the illness in the postsecondary setting;
- Encourage the adolescent to attend and actively participate in IEP meetings;
- Encourage the adolescent to assume self-responsibility and identify ways to transfer responsibility from parent to adolescent prior to the student's arrival in a postsecondary setting; and
- Provide opportunities for the adolescent to use and develop skills necessary to assume responsibility for self. These elements are essential given that interaction in the postsecondary setting is between student and staff, not between parent and staff. In fact, the Family Education and Privacy Act of 1974 precludes information dissemination to parents of individuals 18 years old or older and generally curtails parents' role in advocating for their child's success on campus.

By law, postsecondary institutions will provide reasonable accommodations to a student with a disability if the student identifies a need and provides adequate documentation of his or her disability. This requires that the student know when, to whom, and how to disclose the disability. First and foremost, however, the student must know whether he or she is eligible for services. Inadequate preparation can result in unnecessary frustration, a decline in health, and/or academic difficulties.

High School Personnel

When a student requires accommodations in high school, teachers and counselors can encourage the student's active participation in identifying solutions and accommodations. They can include the student in activities and can promote opportunities for self-advocacy and independence. They also can help educate the student about his or her rights and explain how these rights will change in the postsecondary setting. They also can help the student think about what the illness-related needs might be in a postsecondary setting, and can help the student identify colleges that meet his or her academic criteria as well as health needs. Wherever possible, school personnel should facilitate student participation in all areas of student life. Exemption from academic courses should be the accommodation of last resort.

Transition planning is provided for students who receive services under the Individuals with Disabilities Education Act or Section 504 of the Rehabilitation Act of 1973. Individualized Education Plans (IEPs) are required to address needed transition services by age 16. Students may request these services as early as 14. High school students receiving services under Section 504 may request the development of a transition plan as part of their 504

plan. One part of an IEP or transition plan may include goals and objectives that will help students develop the skills necessary to fulfill their roles and responsibilities in the postsecondary setting.

Comprehensive post-high school planning for students with chronic illnesses who are not receiving special education and related services is rarely, if ever, done in the high school setting. When school-based post-high school planning is provided, it typically is geared toward the general student body. A student's particular illness and associated accommodations are rarely taken into consideration, usually because school guidance personnel are unaware of the illness. Sometimes the student/parents fail to disclose the chronic illness because they do not realize the potential consequences of the illness in a postsecondary setting. Alternatively, the student may be aware of the potential impact but may be unaware of what can be done about it.

Students who do not disclose their illness do not receive illness-specific assistance with transition planning. When considering postsecondary education, students with chronic illnesses may find it beneficial to disclose their illness to their career or college counselor. This professional, who has the appropriate education and training, may help students with chronic illnesses gain a clear understanding of what the postsecondary experience will entail. They also can help them identify how their illness may affect them. Finally, the college counselor may be able to provide resources to promote academic success.

Community Service Providers

Students with chronic illnesses may utilize a variety of services within their local community. It is important for both the student and the family to assess these services and determine whether they will be needed in the postsecondary setting. Community service organizations may be able to provide valuable referral information. For example, a student with epilepsy can use the local epilepsy affiliate as a resource to locate neurologists, support groups, or other necessary services in the new location. Vocational rehabilitation counselors also can be an excellent resource for students moving into the postsecondary setting. (See the discussion of vocational rehabilitation [page 9] for further information.) In fact, community service providers can be part of a transition planning team.

Disability Support Services Staff (DSS)

Students with chronic illnesses may require a variety of accommodations and supports in the postsecondary setting. Students can contact campus DSS staff while considering a college to determine how it would accommodate their needs. By request, DSS staff can facilitate discussions between students with chronic illnesses on campus and prospective students. Once they have accepted an offer of admission, students can work closely with DSS staff to identify and institute necessary accommodations and supports.

Medical Personnel

For students with chronic illnesses, continuing medical care is paramount to maintaining good health and to a successful postsecondary outcome. Parents and medical personnel must ensure that students understand their illness and associated medical needs, both present and future. They also must facilitate development of the students' abilities to interact and communicate with medical personnel about their illness when away from home. Open dialogue about issues related to the illness, its progression and how it may necessitate accommodations, and steps the student must take to ensure optimum health all are important to postsecondary success.

Also important is the development of a plan for each student's medical care in the postsecondary environment. Medical personnel can help the student identify health-related needs, locate resources, select specialists and specialized treatment facilities in the new setting, and communicate critical information about the student's care to medical personnel. Early identification of medical needs, specialists, and resources can help the student assess the community's ability to meet his or her medical needs. Input from medical personnel is crucial to the school selection process, because it helps ensure that needs can be met once the student is in the postsecondary setting.

ELEMENTS OF EFFECTIVE TRANSITION PLANNING

To develop an effective transition plan and to maximize success in the postsecondary education setting, the student must begin to clarify career goals, identify current illness-related needs, anticipate how moving into a postsecondary setting will impact current and future needs, and develop strategies for meeting all of these needs. Thus, the campus's educational program, geography, residential quarters, surrounding community, availability of medical care, and availability of individuals who can provide assistance all must be evaluated.

The following elements of effective transition planning were synthesized from discussions with

college students with chronic illnesses, campus DSS staff, and others involved in postsecondary education. The first four elements address the impact of health-related illness in specific areas: education, environmental considerations, medical needs, and activities of daily living. The remaining elements address the knowledge, skills, and abilities necessary for successfully implementing the transition plan. The student with a chronic illness who is preparing to continue education after high school needs to learn about and be able to use the information, knowledge, and skills identified below.

Education

- Did the illness necessitate any special accommodations in high school?
- Was a class that met at a certain time of day missed because of the student's need to perform a health care routine?
- Did the illness affect the student's overall attendance?
- Did medication affect the student's ability to concentrate or participate in school (e.g., was the student more alert at certain times of the day or were frequent breaks from class required to take medications or to rest)?
- Did the student require extra time to complete class work, tests, or homework?
- Was technology (such as a computer) used in the classroom or at home to fulfill academic requirements?
- Was in-class assistance required, such as a person to take notes?

Environmental Considerations

- Do certain environmental factors (such as heat, cold, molds, dust, odors, and humidity) affect the student's health and well-being?
- Does the student need to limit exposure to noise and distractions?
- Does the student require a special (controlled) living environment?
- Are certain activities (such as walking long distances or climbing stairs) difficult?

Medical Needs

- Is the student restricted from participating in any activities?
- Does the student require specialized medical care facilities (for example, dialysis)?
- Does the student require the coordinated care of many health care providers?
- Does the student have a care routine which must be performed at specific times of day?
- Does the student have a care routine which can be performed only by a specially trained individual, such as a physical therapist, respiratory therapist, or nurse?
- Is there a medication schedule which must be strictly adhered to?
- Are required medications difficult to locate?
- Is the care of a medical specialist required? How frequently?
- How does the student plan to cover medical expenses?

Activities of Daily Living

- Is assistance required in getting out of bed?
- Is assistance with food preparation/eating needed?
- Does the student require a special diet?
- Does the student need assistance in bathing or using the bathroom?
- Is assistance with dressing necessary?
- Is assistance with mobility required?

KNOWLEDGE, SKILLS, AND ABILITIES NECESSARY FOR SUCCESSFULLY IMPLEMENTING THE TRANSITION PLAN

Responsibility for Self

The prevailing expectation in the postsecondary environment and in the adult world is that students will advocate effectively on their own behalf. This is very different from the expectation in high school and from what typically occurs at home. Being aware of this expectation and developing the skills to take responsibility for self are important to student success in postsecondary education. In order to receive any accommodations in the postsecondary setting or in their living environment, students with disabilities must initiate the request. Preparing to take responsibility for one's self must begin early. While still in high school, students should participate actively in the identification of their own needs, and in the development of appropriate accommodations and strategies. They should learn how to locate and access appropriate community resources, develop and use self-advocacy skills, and take an active role in their medical management (e.g., scheduling their own medical appointments, communicating with their physician about their needs, performing health care routines independently whenever possible, scheduling and taking medications, performing therapeutic routines, etc.). Taking responsibility for one's self is essential if the student is to accommodate the effects of the chronic illness in the postsecondary setting successfully.

Civil Rights

Students with chronic illnesses that limit one or more life functions have certain legal rights as persons with disabilities. The Individuals with Disabilities Education Act (IDEA) is the law that governs the education of children and youth with disabilities through high school. The Rehabilitation Act of 1973 (especially Section 504) protects the rights of persons with disabilities in any federally funded entity (including elementary, secondary, and postsecondary education institutions), and the Americans with Disabilities Act extends that protection beyond federally funded entities. However, rights differ dramatically between the secondary and postsecondary settings. Through high school, all students are entitled to a free and appropriate education regardless of disability. IDEA does not apply to students once they have left high school. Students must meet postsecondary institutions' educational and technical standards for admission. Once a student is admitted to college, he or she may be eligible to seek accommodations according to Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act. It is important that students with chronic illnesses learn about the laws that protect them as persons with disabilities. It is equally important that they learn how to apply these laws and how to access needed services.

Disclosure of Chronic Illness

Deciding to disclose the existence of one's chronic illness is a very personal decision. It is important to determine what the student hopes to achieve or receive as a result of disclosure. If any illness-related needs require accommodations, then disclosure clearly will be necessary. Disclosure may be made at several points in the transition process.

Disclosure to one's high school guidance/transition counselor will enable the student to receive specific advice as to how, when, and where to disclose needs to the postsecondary institution and to determine what types of accommodations might be necessary. Counselors also may refer the student to appropriate state agencies, such as the state office of vocational rehabilitation, from which the student may receive valuable direction and services.

Another opportunity for disclosure is often provided at the time admission to college is offered. Many colleges send prospective students a postcard they can return to the institution's DSS office; alternatively, information may be provided on how to contact that office. Note that this disclosure is voluntary, and that it is illegal for a school to use this information to discriminate. Upon disclosure, the DSS office or other appropriate campus office will forward information about DSS and other applicable services. DSS staff strongly encourage students with chronic illnesses to contact them prior to accepting an offer of admission. By doing so, they can discuss accommodations that will be necessary for a successful postsecondary experience and how the institution will meet the student's needs. If the student does not disclose prior to arriving on campus, but will need accommodations, disclosure to the DSS office can and should occur prior to the start of the semester. This will enable the office to establish the student's eligibility for services, identify needs, and develop reasonable accommodations. DSS staff will help facilitate the disclosure process to professors and other representatives on campus who will be involved in providing accommodations. Disclosure must occur whenever a new situation arises in which an accommodation is required.

The student must remember that disclosure in the postsecondary setting is the responsibility of the student, not the institution. No action will be initiated on the student's behalf unless the process is started by the student.

Medical Needs Management

The student's ability to maintain the continuity of health and medical care is crucial to educational success. Planning for medical transition promotes continuity of care. Students with chronic illnesses should discuss postsecondary plans with their primary care and specialty physicians at the outset of the school selection process. They should work with their doctors to determine what their specific medical needs in the postsecondary setting may be–both short- and long-term. In addition to the identification of medical needs, areas to be considered include: identification of, and access to, specialty care in the new setting; transfer of medical records; fostering communication among health care professionals; access to emergency care; and access to specialized services such as pharmacy, dialysis, and therapies. It is important to work cooperatively with health care providers to consider these issues and to develop a plan of action prior to accepting admission to any postsecondary institution. The student may wish to observe campus health services as well as meet any new medical providers prior to the actual transition to establish a relationship and to ensure communication among all involved. Keep in mind that once a student turns 18, the student will be responsible for coordinating medical care, even if parents have done

so in the past. How medical service fees will be covered also must be considered in transition planning. According to campus administrators, the most common sources are family insurance coverage, campus-offered student health insurance, and – if the student is eligible – Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI).

Development of a Network for Transition Planning

Although the student can seek assistance from a variety of sources and individuals when developing a transition plan, three fundamental sources of information exist within the secondary and postsecondary setting.

In high school: The guidance/transition counselor can assist the student with overall postsecondary education planning. The guidance/transition counselor can be instrumental in helping students select postsecondary institutions appropriate for their academic abilities and educational goals. The counselor also can discuss any illness-related accommodations that were made in the secondary setting and that may be beneficial in the postsecondary setting.

If the student has had significant interaction with the high school nurse, the nurse may be a useful participant in transition planning.

Bridge between the secondary and postsecondary setting, independence, and employment: Vocational rehabilitation counselors provide specialized services and assistance to students who are eligible for services. Guidance/transition counselors may be familiar with how the student's illness was accommodated in the secondary setting, but they may not have a thorough understanding of how it may impact the student's transition to a postsecondary environment and employment. It is therefore important for the student to contact the state Vocational Rehabilitation office, where a counselor who understands both disability issues and post-high school settings can help identify illness-related transition needs.

Vocational Rehabilitation is a state agency responsible for helping individuals with disabilities gain suitable employment. To be eligible for services, an individual must have an impairment that constitutes or results in a substantial impediment to employment; be able to benefit in terms of an employment outcome from the provision of rehabilitation services; and require vocational rehabilitation services to prepare for, enter into, engage in, or retain gainful employment. Depending on the state's available resources, and the severity of the student's disability, the student may or may not be approved to receive services. Nevertheless, the student should take the steps necessary to determine eligibility for services. For those who are eligible, postsecondary education can be a viable means of obtaining an employment outcome. Services which may be provided by vocational rehabilitation include assessment, career planning, tuition assistance, acquisition of technology, and development of reasonable accommodations. Fees for some services may be determined on the basis of the individual's ability to pay. Optimally, the student should contact the state Vocational Rehabilitation office at the end of the junior year or at the beginning of the senior year of high school. This will allow adequate time for the Vocational Rehabilitation counselor to determine eligibility and to develop an Individualized Written Rehabilitation Plan (IWRP), which will outline goals and how they will be achieved. In this way, the counselor can help the student with overall transition planning.

In the postsecondary setting: Disability Support Services (DSS) staff can help prospective students identify how illness may impact the experience at that institution and can identify appropriate accommodations and resources. Postsecondary education institutions must comply with Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, as well as with any relevant state and local laws. These laws protect qualified individuals with disabilities against discrimination and require the institution to provide equal access. To be eligible for DSS support, a student must have medical documentation to support his or her claim of a chronic illness. Such documentation usually can be provided by a primary or specialty care physician. Once eligibility is established, DSS staff can help the student identify needs, determine appropriate and reasonable accommodations, develop advocacy skills, and act as a liaison with professors.

Accommodations used in high school may be necessary and appropriate in the postsecondary setting. However, because the postsecondary setting is inherently more complex and integrates many other aspects of life with education, the range of accommodations needed in the postsecondary setting may be much broader. Some examples of accommodations include priority registration, priority parking, classroom services such as notetakers and/or interpreters, testing services such as extended time or a quiet setting, adapted/accessible housing, schedule changes/possible reduction in academic load, relo-

cating classes, telecommuting, extended time for completing assignments, distance learning, medical withdrawal, and extended leave of absence. Creative accommodations, such as substituting summer semester for winter semester in order to maintain full-time status at a campus where cold weather may impact a student's ability to complete studies, also may be possible. The student should be aware that not all schools provide the same accommodations in the same manner. They also do not always provide accommodations exactly as requested. Postsecondary institutions are required only to provide accommodations that are timely and effective. The student must comply with the school's procedures for making needs known and for requesting accommodations. Always, it is the student's responsibility to initiate referral activity and to access these services.

Finally, DSS staff may be able to help the student locate resources and support services, and they also may provide other assistance and information as required.

Assessment of the College's Ability to Meet Student Academic Needs

The academic program desired should be the first consideration in the college selection process. It is important for students to identify their educational goals as well as to assess the school's academic programs, majors offered, admission requirements, cost, size, location, activities/programs of interest, housing, student/teacher ratio, and any other factors deemed important.

From more than 3,000 colleges and universities in the United States, the student must try to select one that will be a good match. An offer of admission to college is based on the student's ability to meet the institution's established academic and technical criteria. The student's acceptance of that offer takes into consideration the institution's ability to provide educational programming as well as disability-related accommodations. Once the student is sure the institution's academic program is appropriate to meet educational and career goals, he or she can work with DSS to develop necessary accommodations.

Assessment of Community Services in the College Location

A postsecondary setting which meets student needs promotes successful experiences. Because the postsecondary setting includes both the school and its surrounding community, students must ensure that the communities in which their postsecondary institutions of choice are located can meet their identified needs. For example, if specialized medical care, support services and resources, and/or specific medical procedures will be necessary, it will be important to determine the community's ability to provide for these needs. The availability of accessible public transportation also is a factor to consider. If the setting cannot adequately meet a student's needs, the student's chances of having a successful experience and completing school may be reduced.

Assessment of the College's Ability to Meet Disability-Related Needs

Although a great deal of information about the postsecondary institution of choice and the ability of DSS staff to assist the student can be obtained by phone or in writing, the best way for a student to assess the school's ability to provide necessary accommodations is to schedule a campus visit. Such a visit will enable the student to see the setting firsthand, and to observe the size of the campus; its location; the accessibility of buildings, housing, medical facilities and specialty care; and campus and community transportation systems. It is critical that the student keep identified needs in mind when determining the ability of the postsecondary environment to meet them. A meeting with DSS staff will enable the student to discuss needs, talk about possible accommodations, and obtain information about community resources. Many DSS staff recommend that the prospective student meet with other students on campus who have chronic illnesses. Such meetings can be arranged by DSS staff and can provide valuable insight into the ability of a postsecondary institution to meet the student's unique needs. The meetings also can provide information about support and advocacy activities in which the student could participate.

Assessment of Health Insurance Coverage

Because adequate health insurance is crucial for students with chronic illnesses, such students must be sure to identify and address health insurance needs. Without adequate insurance, the student may be unable to pay for or access health care or medication, which in turn may negatively impact the student's postsecondary success. The availability of health insurance is linked directly to quality of life and prognosis for individuals with chronic illnesses, so it is vital for students to have a plan for coverage to ensure adequate medical care while in the postsecondary environment.

Family health insurance coverage plans vary among providers, and students frequently "age out" of their families' policies. Many postsecondary insti-

tutions offer group plans for full-time students, but these plans typically have limitations, such as waiting periods for pre-existing conditions. Because students with chronic illnesses may be left without adequate medical coverage, some DSS staff and postsecondary students suggest that students apply for the school's group coverage while they are still covered by their parents' plans. By doing so, they ensure continuous coverage.

When preparing for transition, students with chronic illnesses should examine their current health insurance coverage, that offered by the school, and that offered by other health insurance options in order to ensure that their health insurance needs will be fully addressed. Students should be sure to note information pertaining to the extent of coverage, the period of coverage (e.g., school term vs. school breaks), and anything else that might affect them. In some instances, students must re-apply for plans not automatically continued through the summer. Pre-existing condition clauses and waiting period requirements may again come into play. Students may be able to avoid this by continuing coverage year round, though doing so may increase the cost of coverage substantially.

Assessment of Financial Needs for Education

Most students who choose to pursue postsecondary education explore many ways of financing their education. According to the HEATH Resource Center's *Financial Aid for Students with Disabilities*, financial aid is designed to help individuals meet their educational expenses when their own resources are not sufficient. Students with chronic illnesses may have even greater need to seek financial aid if their illness necessitates payment for accommodations of personal use or study, which colleges and universities are not required to supply, or for the use of needed technologies.

Students can apply for financial aid through the Financial Aid Office of the institution they plan to attend. Some colleges offer scholarships specifically for students with disabilities. Students also may choose to contact national disability organizations, their state Vocational Rehabilitation office, Supplemental Security Income office, Social Security Benefits office, Talent Search, Educational Opportunity Centers, Student Support Services programs on campus, and state programs. They also may choose to pursue private scholarships funded by organizations such as the Lions Club and the Kiwanis Club.

CONCLUSION

Planning to ensure that the development of skills and the acquisition of information necessary to develop and implement an effective transition plan must start early. As children grow into adolescence, activities that expand their responsibilities and ability to function independently must be encouraged. Parents, high school personnel, community service providers, disability support services staff, medical personnel, and any other individual in a position to foster these skills can be a partner in overall transition planning. Educational, environmental, medical, and activities of daily living factors all may be affected by the presence of a chronic illness. Assessing how the illness impacts the student in these four areas, anticipating how needs in the four areas might change in a postsecondary setting, and developing strategies to minimize or alleviate those impacts form the core of a transition plan.

Prior to selecting a postsecondary education institution at which to study, students with a chronic illness should be able to identify their academic goals and the characteristics they desire in a college. Financial and health insurance needs also should be addressed. By the time students are in the postsecondary setting, they should be able to take responsibility for self; understand their rights as persons with disabilities, as well as any disability-related accommodative needs; be able to advocate to have their needs met; have a plan for meeting medical needs; know when and how to disclose illness in order to arrange accommodations; be able to identify and access services; and have community supports and resources in place.

Although students with chronic illnesses face many challenges in the postsecondary environment, effective transition planning can increase their opportunities for success and result in a satisfying postsecondary experience.

REFERENCE

[1] Blum, R. W. & Gehn, O. Chronically ill youth: In: McAnarney ER, Kreipe RE, Orr DP, Comerci, GD, eds. Textbook of adolescent medicine. London: W B Saunders Company, 1992:222-8.

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SELECTED RESOURCES

Organizations and Agencies

Adolescent Employment Readiness Center
Children's National Medical Center
111 Michigan Avenue, NW
Washington, DC 20010-2970
(202) 884-3203
E-Mail Address: AERCCNMC@aol.com
Provides prevocational and vocational counseling for adolescents and young adults 12-21 years old with chronic illnesses and physical disabilities to help them learn about their interests, strengths, and abilities; develop realistic career goals; prepare for transition to postsecondary education, employment, and independence; and learn how their illness or disability may impact their career plan.

American College Health Association (ACHA)
P.O. Box 28937
Baltimore, MD 21240-8937
(410) 859-1500
E-Mail Address: ACHA@access.digex.net
A nonprofit organization that promotes excellence in college health by setting standards and providing quality programs and services to colleges and universities. The mission of the association is to be the principal advocate and leadership organization for college and university health. It provides advocacy, education, and services for its members to enhance their ability to improve the health of all students and the campus community.

Council of State Administrators of Vocational Rehabilitation (CSAVR)
P.O. Box 3776
Washington, DC 20007
(202) 638-4634
Contact to locate individual state Vocational Rehabilitation programs.

Disability Rights Education and Defense Fund (DREDF)
2212 6th Street
Berkeley, CA 94702
(800) 466-4232
This national center focuses on law and policy issues related to the rights of individuals with disabilities.

Distance Education and Training Council (DETC)
1601 18th Street, NW
Washington, DC 20009
(202) 234-5100
http://www.detc.org
This nonprofit educational association serves as a clearinghouse of information about the distance study/correspondence field, and sponsors a nationally recognized accrediting agency, The Accrediting Commission of the Distance Education and Training Council.

Federal Financial Aid Information
Toll free number: (800) 433-3243 (V);
(800) 730-8913 (TTY)
To download a FAFSA form electronically:
www.ed.gov/office/OPE/express/html

HEATH Resource Center
American Council on Education
One Dupont Circle, Suite 800
Washington, DC 20036-1193
(202) 939-9320 (V/TTY)
E-Mail Address: heath@ace.nche.edu
http://www.ACENET.edu
Gopher Address: gopher://bobcat-ace.nche.edu
HEATH is the national clearinghouse on postsecondary education for individuals with disabilities. Available from HEATH are free telephone consultation and numerous publications (nominal cost-recovery prices) on a variety of topics related to education after high school for people with disabilities. Publications of particular interest to readers of this paper include *Vocational Rehabilitation Services: A Consumer's Guide for Postsecondary Students* ($2), *How to Choose a College: Guide for the Student with a Disability* ($1), and *Financial Aid for Students with Disabilities* ($2).

National Council on Independent Living (NCIL)
310 South Peoria Street, Suite 201
Chicago, IL 60607
(312) 226-1006
Contact for information on Independent Living Centers in your state.

National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013-1492
(800) 695-0285
E-Mail Address: nichcy@aed.org
http://www.nichy.org
Gopher Address: gopher aed.org
NICHCY is the clearinghouse that provides information on disabilities and disability-related issues concerning children and youth with disabilities.

The National Transition Alliance for Youth with Disabilities (NTA)
University of Illinois
Transition Research Institute
51 Gurty Drive
Champagne, IL 61820
(217) 333-2325
E-Mail Address: leachlyn@uxl.cso.uiuc.ed
http://www.aed.org/Transition/Alliance/NTA.html
NTA promotes the transition of youth with disabilities toward desired post-school experiences, including gainful employment, postsecondary education and training, and independent living. Also provides technical assistance to link personnel responsible for providing transition services and model transition programs.

Technical Assistance Alliance for Parents Center (The Alliance)
Parent training and information centers in each state provide training and information to parents of infants, toddlers, children, and youth with disabilities and professionals who work with parents. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. To reach the parent training and information center in your state, contact the Technical Assistance Alliance for Parents Center (The Alliance), which coordinates the delivery of technical assistance to the parent training and information centers through four regional centers located in California, New Hampshire, Texas, and Ohio.

Alliance Coordinating Office:
Pacer Center
4826 Chicago Avenue South
Minneapolis, MN 55417-1098
(612) 827-2966 voice
(612) 827-7770 TTY
(612) 827-3065 fax
(888) 248-0822 (nationally)
E-Mail Address: alliance@taalliance.org
www.taalliance.org

Northeast Regional Center
Parent Information Center
P.O. Box 2405
Concord, NH 03302-2405
(603) 224-7005 voice
(603) 224-4365 fax
E-Mail Address: picnh@aol.com

South Regional Center
Partners Resource Network, Inc.
1090 Longfellow Drive, Suite B
Beaumont, TX 77706-4819
(409) 898-4684 voice
(409) 898-4869 fax
E-Mail Address: TXPRN@juno.com
CT, DE, DC, ME, MD, MA, NH, NY, AL, AK, FL, GA, LA, MS, NC, OK, SC, PA, PR, RI, VT, VI,TN, TX, VA, WV

Midwest Regional Center
Ohio Coalition for the Education of Matrix Parent Network and Resource Center
555 Northgate Drive, Suite A
Marion, OH 43302-3741
(408) 499-3877 voice
(408) 507-9457 fax
E-Mail Address: matrix@marin.k12.ca.us

West Regional Center
Children with Disabilities (OCECD)
Bank One Building
165 West Center Street, Suite 302
San Rafael, CA 94903
(614) 382-5452 voice
(614) 383-6421 fax
E-Mail: oceed@edu.gte.net
AK, AZ, Department of Defense Dependent
CO. IL, IA, IN, KS, KY, MI, MN, MO Schools
(DODDS), CA, HI, ID, MT, NV, NM, NE, ND, OH,
SD, WI, OR, Pacific Jurisdiction, UT, WA, WY

U.S. Department of Education
Family Compliance Policy Office
Washington, DC 20202
(202) 260-3887
Contact for information on the Family Educational Rights and Privacy Act of 1974.

U.S. Department of Education
Office of Civil Rights
Suite 5000
330 C Street, SW
Washington, DC 20202-1100
(202) 205-5413
E-Mail Address: OCR@Ed.Gov.
Enforces the federal civil rights laws that prohibit discrimination on the basis of race, color, national origin, sex, disability, and age in programs and activities that receive federal financial assistance.

U.S. Department of Justice
Office of the Americans with Disabilities Act
Civil Rights Division
Post Office Box 66118
Washington, DC 20035-6118
(202) 514-0301
http://www.USDOJ.GOV/CRT/ADA/ADAHOM1.m
Contact for information about the Americans with Disabilities Act.

PUBLICATIONS

Two publications that focus on postsecondary institutions and disability laws are *Subpart E: The Impact of Section 504 on Postsecondary Education* and *Title by Title: The ADA and Its Impact on Postsecondary Education*, both by Jane Jarrow and available for $20 each from the Association on Higher Education And Disability (AHEAD), P.O. Box 21192, Columbus, OH 43221. (614) 488-4972.

Garwick, Ann & Millar, H.; *Promoting Resilience in Youth with Chronic Conditions & Their Families, April 1996, U.S. Department of Health & Human Services* is a booklet that focuses on strategies for families and medical personnel to promote family-centered care as young people move from childhood through adolescence. It is available from:

Health Resources & Services Administration
Maternal and Child Health Bureau
National Center for Youth with Disabilities
University of Minnesota
Box 721, 420 Delaware Street, SE
Minneapolis, MN 55455
(800) 333-6293

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Authors of *Maximizing Success for Young Adults with Chronic Health-Related Illnesses: Transition Planning for Education After High School* and staff of the Adolescent Employment Readiness Center of the Children's National Medical Center have been superior collaborators on the development of this HEATH Resource Paper. The generosity of Ciba Pharmaceutical for funding the research and writing of this publication is gratefully acknowledged.

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The HEATH Resource Center operates the national clearinghouse on postsecondary education for individuals with disabilities. Support from the U.S. Department of Education enables the Center, a program of the American Council on Education, to serve as an information exchange on educational support services; policies and procedures; adaptations; and opportunities at American campuses, vocational-technical schools, adult education programs, independent living centers, and other postsecondary training entities. This information assists people with disabilities in developing their full potential through postsecondary education and training.

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Please mail order form and payment to:
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Washington, DC 20055-0036

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___ (CI) Maximizing Success for Young Adults with Chronic Illness
___ (CPP) Career Planning and Employment Strategies
___ (DB) Students Who Are Deaf/Blind on Campus
___ (DHH) Students Who Are Deaf or Hard of Hearing
___ (DL) Adults With Disabilities and Distance Learning
___ (ESLD) Educational Software for Students w/LD
___ (FA) Financial Aid for Students w/Disabilities
___ (GR) Getting Ready for College: Advising Students w/LD
___ (LD) LD Adults in Postsecondary Education
___ (MSP) Measuring Student Progress in the Classroom
___ (MTM) Make the Most of Your Opportunities
___ (OSN) Young Adults w/LD & Other Special Needs
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___ (PVR) Vocational Rehabilitation Services
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___ (CC) Community Colleges & Students With Disabilities
___ (CD) Career Development
___ (CTD) Computers, Technology & People w/Disabilities
___ (EDL) Disability Law/Emerging Issues
___ (FAC) Facts You Can Use or "Stat Pack"
___ (GTM) Get the Most Out of College: Mobility Limitations
___ (LDHA) LD Among High Achieving Students
___ (LS) Students w/Disabilities and Law School
___ (MCS) Students w/Multiple Chemical Sensitivity
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